

What are the VA Multiple Sclerosis Centers of Excellence?

The Multiple Sclerosis Centers of Excellence (MSCoE) established by the Veterans Health Administration (VHA) in 2003 are committed to serving the health care needs of approximately 35,000 veterans with MS. The Centers of Excellence are located in Seattle and Portland (MSCoE West) and Baltimore (MSCoE East). The Centers of Excellence are dedicated to understanding the disease and its impact on veterans, and offering treatments to help manage MS symptoms and prevent disability. By partnering with veterans, caregivers and health care providers, the Centers hope to minimize disease impairment and increase the quality of life for veterans with MS.

The MS Centers of Excellence are organized around 4 cores: Clinical Care, Education & Training, Research, and Informatics/Telemedicine. The goal of the Clinical Care core is to improve MS services locally and nationally, based on the needs of veterans and health care providers. We provide state-of-the-art multidisciplinary health services for veterans with MS and serve as a prototype for excellent clinical care throughout the VA. Our objective is to ensure that all veterans with MS have access to care that

meets established standards.

The goal of the Education and Training core is to increase health care provider and patient knowledge, self-efficacy, and access to resources. Our programs are designed to address the educational needs of veterans, their caregivers and health care providers, and empower veterans and their caregivers to participate actively in their healthcare.

The Research core coordinates clinical and research programs to enhance participation of veterans in clinical trials, incorporate findings of relevant research into the clinical care of veterans, and establish a research agenda that addresses the unmet needs of veterans with MS.

The Informatics/Telemedicine core goals are to develop intranet and internet web presence for veterans, caregivers, providers, and other interested parties and use our website to inform individuals about MS and new treatments.

Visit our website (<u>www.va.gov/ms</u>) for more information about the VA MS Centers of Excellence and MS.

Photo above: Skybridge connecting the Portland VA Medical Center and Oregon Health & Science University in Portland, OR

VA MS Patient Education Conference Calls

Date/Time: The 2nd Monday of each month from 8:00-9:00pm ET **Dial in number:** 1-800-767-1750 Then dial access code: 43157# **To Participate:** Contact Angela Young at 1-800-463-6295 x.7133



Visit our Website!

Please visit the VA MS Centers of Excellence Website for additional information at www.va.gov/ms.

What's Inside

- **■** The MS Centers of Excellence
- **■** About Multiple Sclerosis
- Online VA Services for MS
- Events
- CAM Therapies in MS
- Questions and Answers
- Disease Modifying Therapies

www.va.gov/ms

What is Multiple Sclerosis?

Multiple sclerosis is a complex disease that affects the central nervous system (brain, spinal cord, and optic pathways). It is typically characterized by relapses (neurologic symptoms which appear rapidly over a few days and then improve to some extent over weeks or months), and remissions (periods of time that are without new symptoms). The disease is unpredictable and some people experience a variety of symptoms that can worsen (progress) over time.

What Causes Multiple Sclerosis?

The ultimate cause of MS is still unknown. Research suggests that some sort of exposure in the environment triggers MS in genetically susceptible individuals. The environmental trigger is uncertain but many believe it is some sort of viral infection that occurs before the age of 15. Research also indicates that several genes working together influence the risk of developing MS. So far only one of these genes has been identified. It is called HLA-DR2 and is associated with an increased risk of developing MS in Northern Europeans and their descendents in North America. Much research is being done to identify other genes that affect the risk of developing MS.

Types of MS: Relapsing-Remitting, Secondary Progressive and Primary Progressive

The course of MS varies widely among individuals with the disease. About 85% of people with MS start out with a pattern of disease that is known as relapsing-remitting. This means that symptoms develop over a few days—called a relapse or attack—, remain for several weeks or months and then resolve either completely or partially. Over time, people who have relapsing-remitting MS have fewer relapses, but may develop permanent disability from the various attacks that have occurred. Many people with relapsing remitting MS evolve into another pattern of disease in which there is progressive worsening. This type or course of MS is known as secondary-progressive, meaning after having relapsing-remitting MS, the individual now experiences steady progression of symptoms over time. People with secondary-progressive MS may or may not continue to have relapses. About half of those who start with relapsing-remitting MS will change to a secondary-progressive disease course 10 to 20 years after onset of their MS. A smaller percentage of patients, about 15%, have a progressive course at the very beginning of their MS, called primary progressive. These individuals have slow changes in function over time. Usually this is noticed as a progressive difficulty in mobility such as walking.

Questions & Answers

I am a veteran with MS. What benefits am I elegible for with the VA?

If you had symptoms of MS in the military or within seven years after honorable discharge, you may be eligible for service-connected disability, including medical care, medications and equipment. However, eligibility for care at a VA facility is NOT contingent on a determination for service connected disability. Rather, the eligibility is based on processing of an application for medical benefits. To determine your eligibility for service connected and non-service connected benefits you need to apply for health benefits. There are several ways for you to enroll.

You can enroll at any VA medical center or you can go online and complete an Application for Health Benefits (Form 10-10EZ) to expedite the process at http://www.va.gov/healtheligibility/HECHome.htm.



If you are elegible to receive services at the VA, disease modifying therapies (DMTs) for MS are routinely available to veterans whether or not they are service connected. Typically

prescription co-pays in the VA are \$8 per prescription per 30 days supply. For those who are unable to pay the medication co-pay, an application for co-pay waiver can be submitted (Financial Status Report, VA form 4-5655) to the office at your local VA medical facility.

For additional information or to find out if you qualify for VA health benefits, please visit your local VA facility or access the health benefits forms online at (http://www.va.gov). Veterans service organizations, such as the Paralyzed Veterans of America (http://www.pva.org/), United Spinal Association (http://www.unitedspinal.org/), & Disabled American Veterans (http://www.dav.org/) are also good resources.

Online Services for Veterans with MS

The VA and other organizations have a number of excellent online resources available to veterans with MS. Some of the major ones are listed below:

- · Neurology: Center for Neuroscience and Regeneration Research
- · Psychological Services: The Mental Illness, Research & Clinical Education Centers
- · Physical Therapy: **CHAMPVA Policy Manual**
- · Recreational Therapy: Recreation/Creative Arts Therapy Service
- · Injection Clinics: Managing Injection Site Reactions
- · Bladder and Bowel Management Programs: Bladder Management in MS
- · Speech and Swallowing Programs: American Speech-Language-Hearing Association
- · Mobility Devices: Transporting a Scooter or Power Wheelchair
- · Wheelchair Clinics: Center for Wheelchair Related Technology

Please visit the MSCoE website at www.va.gov/ms for direct links to these sites. Click *About MSCoE*, then click *Our Programs*.

MS DVD's Available

The MS Centers of Excellence produced and recorded DVD's from our live satellite broadcasts. If you are interested in receiving these free DVD's from the MSCoE, please contact <u>Jay.Blazey@va.gov</u>. See program titles below:

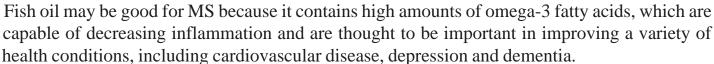
- Fatigue & Cognitive Effects of Multiple Sclerosis
- Treating Multiple Sclerosis: *Making a Difference in Veteran's Lives*
- Sexual Intimacy & MS

Complementary & Alternative Therapies in MS Fish Oil and MS

Lynne Shinto, ND

MS Center of Oregon

Fish oil may be good



One published research study in MS and preliminary data from a study we conducted at the MS Center in Portland show a decrease in the levels of inflammatory agents after three months of fish oil supplementation. The inflammatory agents measured in both studies are the same ones associated with the MS disease process.

There are two types of omega-3 fatty acids found in both fish and fish oil that are thought to contribute to maintaining healthy neurons. Eicosapentaenoic acid (EPA) is a strong anti-inflammatory agent that has been found in studies of depressed patients without MS to decrease depression significantly when added to antidepressant medication. Docasahexaenoic acid (DHA) is the major fatty acid found in neuronal membranes and is thought to be important in improving memory problems from age-related dementia.

Although more research studies are needed to better evaluate the benefit of fish oil in MS, fish oil added to standard conventional MS therapies appears to be safe and may be beneficial for MS. The recommended dose is 3 grams of fish oil per day containing a daily dose of 1000 mgs of EPA and 750 mgs of DHA.

Treating MS with Disease Modifying Therapies: Current Update

Dennis Bourdette, MD, VA MS Center of Excellence West

Before 1993 there were no treatments that could alter the natural course of MS. Since 1993, the Food and Drug Administration (FDA) has approved six drugs for the treatment of relapsing forms of MS. These drugs include three types of interferon beta (interferon beta-1b, Betaseron and two formulations of interferon beta-1a, Avonex and Rebif), glatiramer acetate (Copaxone), mitoxantrone (Novantrone) and natalizumab (Tysabri).

All of the FDA approved medications, known as disease modifying therapies (DMT's), decrease the number and severity of relapses and most have been shown to decrease the risk of developing permanent disability. These drugs modify the course of MS by modulating the immune system. None of these medications are cures. The medications differ in side-effects and long term risks. All of them are available through the VA.

Currently, the "first line" treatments for relapsing forms of MS (relapsing remitting MS or secondary progressive MS with superimposed relapses, see article on page 2) are the interferons and glatiramer acetate. Because of safety concerns, mitoxantrone and natalizumab are reserved for people with very active relapsing MS who have not responded to interferons or glatirmer acetate or cannot tolerate these medications. Mitoxantrone is also used to treat people with secondary progressive MS, even if they no longer have relapses. There are currently no FDA approved treatments for primary progressive forms of MS.

The Interferons

Interferon beta is a protein that cells in our bodies make. Interferon beta helps MS by inhibiting the activity of disease causing white blood cells and stimulating the production of protective substances. All three forms of interferon beta are given by self-injection but differ in where they are injected (under the skin for Betaseron and Rebif or in the muscle for Avonex) and how often it is given (every other day for Betaseron; three times a week for Rebif; once a week for Avonex). The main side-effects of the interferons are "flu-like" reactions (muscle aches, fever, fatigue), irritation of the liver, lowering of blood counts, and reactions at injection sites (for the two given

under the skin). In some individuals, depression can also be a side effect of interferons.

Glatiramer acetate

Glatiramer acetate is a synthetic protein made from four amino acids. It helps MS by stimulating protective white blood cells and "blocking" disease causing white blood cells. It is given once a day under the skin. The main side-effect of glatiramer acetate are reactions at the injection sites. Because it is not an interferon, it does not cause "flu-like" side-effects or affect blood counts or the liver.

Mitoxantrone

Mitoxantrone is a chemotherapy drug. It helps MS by suppressing the immune system. It is given by intravenous injection every three months. People typically receive it for one to three years. The possible side-effects of mitoxantrone include nausea and vomiting, hair loss, low white blood cell counts and infections. Mitoxantrone can damage the heart so there is a limit to how much mitoxantrone a person should receive. There is also a risk of mitoxantrone causing leukemia, which is usually fatal.

Natalizumab

Natalizumab is one of a class of relatively new medications called "monoclonal antibodies." These are proteins that bind to specific substances in the body. Natalizumab binds to a protein on white blood cells and interferes with their ability to enter the brain and spinal cord. By doing this, natalizumab prevents disease causing white blood cells from getting into the nervous system and causing damage. Natalizumab is given by intravenous injection every four weeks. Side-effects at the time of infusion include allergic reactions. Natalizumab has resulted in a rare, serious and often fatal viral infection of the brain, called PML (progressive multifocal leukoencephalopathy). Because of the risk of PML, there is special program for monitoring people receiving natalizumab, called the TOUCH program. Because of concerns about long term safety, natalizumab should be reserved for people with relapsing MS who have failed treatment with the first line therapies, interferon beta and glatiramer acetate, or who are unable to tolerate these medications.

For more information about these treatments, talk with your doctor and go to our website at www.va.gov/ms.

Educational Presentations available on the Web

- Men with MS & Finances
- Social Support in MS
- Vocational & FinancialConsiderations in MS Rehab
- What's New, What's Hot, What's Not: Multiple Sclerosis in 2006
- From the Lab to the FDA to You
- Integrative Medicine: Advances in Alternative Therapies for MS
- Mitochondria: Is it the Key to Protecting Your Brain?

Go to www.va.gov/ms



The Paralyzed Veterans of America, a congressionally chartered veterans service organization founded in 1946, has developed a unique expertise on a wide variety of issues involving the special needs for their members—

veterans of the armed forces who have experienced spinal cord injury or dysfunction, including injury caused by MS. PVA uses that expertise to be the leading advocate for: quality health care for their members, research and education addressing spinal cord injury and dysfunction, benefits available as a result of their members' military service, & civil rights and opportunities which maximize the independence of their members. For additional information, please visit their website at www.pva.org.

NATIONAL EVENTS

The National Veterans
Wheelchair Games
Location: Milwaukee, WI
Date: June 19-23, 2007.

Information: For veterans who are interested, please contact your physician or theraputic recreation at your facility, or visit the following website: http://www1.va.gov/vetevent/nvwg/

2007/default.cfm

The National Disabled Winter Sports Clinic Location:

Snowmass Village, CO **Date:** April 1-6, 2007

Information: For veterans who are interested, please contact your physician or theraputic recreation at your facility, or visit the following website: http://www1.va.gov/vetevent/wsc/2007/default.cfm



United Spinal Association is a 501(c)(3) nonprofit membership organization. Their mission is to provide expertise, create access to resources and strengthen hope thereby enabling people with spinal

cord injuries and disorders (SCI/D) to fulfill their potential as active members of their communities. They accomplish their mission by:

- Ensuring quality health care
- · Promoting research
- · Advocating for civil rights and independence
- Educating the public and enlisting its help
- Expanding opportunities for all paralyzed Americans For additional information, please visit their website at www.unitedspinal.org.

Questions or Comments?

Suggestions for the next issue of the MSCoE Veteran Newsletter? If so, we would love to hear from you! Please mail the attached comment card *OR* submit your comments online at www.va.gov/ms



Portland VA Medical Center 3710 SW US Veterans Hospital Road Mail Code: P3COE Portland, OR 97239

Joe Smith 5555 Smith Road Smithville, NJ 00000